# 20 22 Impact Report

# Supporting Family Caregivers through Education, Understanding, and Action





## Introduction

# The National Initiative for Eating Disorders (NIED) exists to give hope and support to individuals with an Eating Disorder and their caregivers.

Since 2012, we have delivered over seventy free, evidence-based and evidence-informed educational symposia about Eating Disorders care, support and recovery. Through our Initial Point of Contact Program, we have answered thousands of calls and emails from family caregivers desperate to help an individual with an Eating Disorder and unsure about who to turn to. With NIED, they find confidential, empathetic, individuals with lived-experience, and high-level guidance as to where and how to seek out professional support.

In September, 2022, we received certification as a Canadian registered charity, and since that time we've been working to more clearly define our focus on providing resources, programs, and initiatives to family caregivers so that they can better support their loved one's recovery.

Our VISION is that Canadians impacted by Eating Disorders receive the care they need. We do this by focusing on our MISSION of being a catalyst for change.

We develop and deliver educational resources, raise awareness, connect with and support family caregivers (e.g. parents, siblings, grandparents, etc.), conduct or participate in research, and initiate a wide variety of actions to address the needs of Canadians impacted by Eating Disorders.

"I just wanted to let you know that L is now in "recovery" and she's in a really good place. I wanted to thank you for taking the time to speak to me, and for reaching out to me to check in. This whole process has been so difficult and speaking to someone who has lived it was so helpful.

More than you'll know."

D. W.

# Chair's Message

# It is a privilege for me in my role as NIED's Chair to address you through our 2022 Annual Impact Report.



I am so very proud to serve with a compassionate and qualified Board of Directors and cohort of volunteers that has turned the challenges presented by COVID into opportunities in support of the NIED Mission of being a catalyst for change.

This report is a snapshot of the impact we have had on those challenged with their Eating Disorder and especially the challenges of the Caregiver community - our focus this past year. Throughout this report you will learn more about the development of our online Educational Tools, the comfort provided through our Initial Point of Contact

and HandKnit Hope programs, our lead role and participation in ongoing research and webinars, our ever-growing relationships with private, public and government agencies, and perhaps most importantly, being at the other end of the phone when someone reaches out in need, simply to listen and know they are heard.

To you, our readers, thank you for your ongoing support; support vital to achieving our Vision to ensure that Canadians impacted by Eating Disorders receive the care they need and deserve. Looking into the rear-view mirror through our Impact Report provides you with the knowledge and our pride in the history we have made. Please join us as we now look forward to creating another chapter in NIED's history.

Respectfully yours,

#### **Lorne Bernstein**

Chair

# Why is our work important?

When people think about caregivers, chances are they think about seniors being looked after by their 'children' or an older adult. Caregiving for individuals with Eating Disorders often doesn't come to mind.

That is why NIED connects with other caregiver organizations to shed light on the unsung population of family caregivers trying to make sense of a devastating and confounding illness.

To put this into perspective, here are some alarming facts about Eating Disorders in Canada.

When a loved one has an Eating Disorder, the impact on families and relationships can be very significant. Too often, stigma, shame, and guilt leads to parents being blamed for their child's illness, and this can make family caregivers reluctant to reach out to others for help and support.

We know that families are suffering. In Canada, an estimated 2.7 million people are living with this serious mental illness, with approximately 1.4 Million of these people being youth. Eating Disorders have the second highest mortality rate of any mental illness, second only to opioid addiction. Amongst those with an Eating Disorder, suicide is the second leading cause of death.

- Even though the pandemic put a spotlight on Eating Disorders, leading to more awareness and a
  significant increase in hospital admissions and emergency room visits, only 10% of sufferers receive
  appropriate treatment, and an even smaller proportion are able to access early intervention services.
  Many of us know from personal experience that the impact on family caregivers is overwhelming,
  serious and traumatic.
- The total number of family caregivers in Canada is staggering. The 2018 Statistics Canada *General Social Survey on Caregiving and Care Receiving* estimated that one in four Canadians of working age is a caregiver. This means that an estimated 5.2 million working people, aged 19 to 70 were family caregivers.

# Our Programs and Initiatives

NIED is making a difference.

**WE ARE:** 

**Developing educational resources for family caregivers.** 

Supporting family caregivers through our Initial Point of Contact Program.

**Providing comfort to both sufferers and their caregivers** through our Hand Knit Hope Program.

Raising awareness to reduce stigma and increase access to community-based programs that focus on early intervention, treatment, and support.

Participating in, and leading Eating Disorders-related research into topics such as the *Impact of Virtual Caregiver Support Groups* (McMaster University-led), and *The Identification of Research Priorities* (Mental Health Research Canada and the University of Calgary). Both of these studies prioritize the importance of the lived experience that caregivers bring to the table.

Continuing to collaborate and mobilize community-based Eating Disorders organizations across Canada on issues of common interest. This includes the past development of the Canadian Eating Disorders Strategy and Eating Disorders Awareness Week.

"I just wanted to say I found last night's event very powerful and engaging. It was a strong reminder of how important this work to provide appropriate supports for both those with the disorder as well as those around them is. I was grateful to them for sharing their story, as well as the discussion panel afterwards."

- SARAH

### **Our Priorities**

#### 2022 was a year of transition. Our priorities were to:



Obtain recognition as a Canadian registered charity so that we ensure long-term sustainability and impact.



#### **Develop educational resources for family caregivers.**

• We introduced a tool for family caregivers, focusing on safety, crisis readiness, and other essential information. Read Caregiver Safety, Crisis Readiness Tool



#### **Support Family Caregivers through our Initial Point of Contact Program.**

• In 2022 we continued to respond to ongoing enquiries from texts, phone calls, emails and through social media.



#### Raise awareness to reduce stigma and increase access to community-based **programs** that focus on early intervention, treatment, and support.

- We continued to develop and to participate in educational webinars designed to educate family caregivers and other key service providers. Here are a couple of highlights from 2022:
- Both NIED's President and Executive Director participated in The Ontario Caregiver's Organization's webinar, Caregiving and Eating Disorders: Expect the Unexpected focused on the caregiver's role in supporting recovery from an Eating Disorder and strategies and resources, including caring for others and self.
- We continue to bring the caregiver experience to health sciences students participating in the University of Toronto's *Understanding Patient/Client* Partnerships in a Team Context. This learning activity brings together students from eleven health sciences programs so that they can learn about the caregiver/ patient experience, and the importance of integrative services, across the continuum of health care needs.

#### Our Reach



#### **Hand Knit Hope**

Our Hand Knit Hope program focuses on providing a sense of warmth, comfort, and love to those impacted by an Eating Disorder. To do this, caregivers or others connected to someone with an Eating Disorder, knit, crotchet and distribute handmade gifts of scarves, neck warmers, headbands, hats, and

During the height of the COVID Pandemic, Eating Disorder programs and support groups were either in isolation or conducted virtually. Consequently, over 300 Hand Knit Hope items were donated to women's shelters, a shelter for homeless and street-engaged youth in Ottawa, the Out of the Cold program, and the Barbra Schlifer Clinic in Toronto. Some items were individually mailed to those who reached out through our Initial Point of Contact program with a personal note.

In 2022, we sent 15 boxes of our Hand knit Hope items to organizations across the country providing community-based services and supports to those impacted by an Eating Disorder.

#### **2022 Eating Disorders Awareness Week**

During the 2022 Eating Disorders Awareness Week, NIED joined other Canadian organizations in a national week of action. This year's theme, "Everyone Has a Role To Play", aimed to recognize that we all have a role to play in Eating Disorder prevention and recovery. Together we created three tools to help support the role played by both those living with an Eating Disorder, and by those caring for someone else. For more information, please visit the NEDIC website.

#### Social Media and Website in 2022



Instagram: Reach increased by 421%



Facebook: Page views increased by 64%, and our reach was up almost 300%.



Twitter: Tweets were up 650%. Impressions were up almost 400%. Profile visits were up 218%.



NIED's Website: In 2022, 19,987 users visited the site, with 86% being new users. Over 40,700 page views were recorded. The most visited page was About Eating Disorders in Canada, with the Home Page, Immediate Support, Participate in Important Eating Disorder Studies, and Resources rounding out the top five page visits.

### **Our Finances**

In September, 2022, we received recognition as a Canadian registered charity. Since that time, we have developed a fundraising strategy that includes CanadaHelps as our giving platform.

#### **Summarised Balance Sheets \***

	December 31		May 31
	2021	2022 **	2023
Current Assets			
Bank Accounts			
Chequing	\$10,273	\$10,568	\$8,560
GIC's	\$20,690	\$30,418	\$47,000
TOTAL	\$30,963	\$40,986	\$55,560
Equity			
Opening Balance	\$17,651	\$30,963	\$40,986
Net Income for Period	\$13,312	\$10,023	\$14,574
TOTAL	\$30,963	\$40,986	\$55,560

<sup>\*</sup> As the annual revenue threshold for Charities to be audited is \$250,000 the above results have not been audited. However all annual tax returns and reports have been prepared and filed on time by professional accountants.

#### **Comments**

As can be seen from the above results, the organization is soundly based and growing.

Since acquiring charitable status in July 2022, we have developed a strong fundraising strategy that includes CanadaHelps as our giving platform together with other efforts to increase our revenue.

Our annual 2023 budget calls for revenue of \$112,000 with expenditures on programs and administration of \$88,000 for a surplus of \$24,000 for the year.

# Measuring Progress

KEY INDICATOR	ACTIVITY / PROJECT	DATA / OUTCOME
An increase in the number of Canadians accessing our supports and services.	All NIED programs and services.	More Canadian family caregivers have access to tools and resources that will help them support a loved one during recovery.
The percentage of parents and other family caregivers who report feeling better equipped to support the recovery of a loved one after accessing our services.	All NIED programs and initiatives.	NIED's services are effective and have a positive impact on family caregivers.
The percentage of parents and other family caregivers who report understanding more about eating disorders and how to access resources as a result of our services.	All NIED programs and services.	More family caregivers know how to access resources, and have a deeper understanding about eating disorders.

"Thank you for your dedication to such an underacknowledged illness. It's individuals like yourself that make the world a better place Wendy. I hope one day we will meet so I can help with your cause."

- R. M.

<sup>\*\*</sup> In July 2022, NIED received recognition as a Canadian registered charity.

# **Executive Director's Message**

Since November, 2020, I've had the honour of working with the incredible team of volunteers that continues to make a difference through their passion, commitment, and hard work.



I want to thank these volunteers, and the members of our Board of Directors, for choosing to spend their time working with us. Together, we are having a significant impact on the lives of those affected by Eating Disorders.

In 2022, we focused on our mission of being a catalyst for change. Although we continued to raise awareness and advocate for better access to care, our primary focus shifted to providing resources, programs, and tools to family caregivers so that they can better support their loved one's recovery. We are continuing with this focus

and, as someone with lived experience as a caregiver, I'm excited about the path that we're on.

One of the year's many highlights was receiving certification as a Canadian registered charity. I want to thank our co-founders, Wendy Preskow and Lynne Koss, for their vision, courage, and unwavering determination that led NIED to this point. Their work over the past eleven years has been truly inspiring, and has made a difference in the lives of people from across the country.

Looking ahead, I know that NIED's future is bright. Over the coming year, we will expand our programs and initiatives so that even more family caregivers have access to the education resources, information, and tools required to care for both themselves and their loved-one. We will also continue to advocate for change, and will expand our reach so that more Canadians impacted by Eating Disorders receive the care they need.

Lastly, I would like to extend my heartfelt thanks to our generous supporters and donors. Your financial contributions are enabling us to fund our programs and services. It's your belief in our work that allows us to continue, and we are truly grateful for your ongoing support.

Sincerely,

Michelle D'Amico Executive Director

"I attended the webinar last week on Caregiving and Eating Disorders and wanted to thank you for such an excellent presentation. You and Michelle spoke so thoughtfully about your experiences — it made me a bit emotional. As an anorexia survivor, I joined the webinar to learn more about the caregiver experience since my family was integral to my recovery when I was a teenager."

- C. G.

# Acknowledgement

# Thank you to our 40+ volunteers, including the members of our Board of Directors.

NIED is enormously grateful to each and every donor for their invaluable support to assist us in our efforts to improve the lives of those impacted by Eating Disorders and those who care for them. Our ability to succeed is intrinsically linked to your support.

Our founder, Wendy Preskow, recently acknowledged our volunteers and supporters by thanking them for the 'countless hours, ideas, decisions, comments, time away from families, researching, editing, sharing and "zooming".

Thank you to all of our individual and corporate supporters. As a monthly or one-time donor, we appreciate your support and continue to make a difference because of you.

As Winston Churchill so poignantly once said, "We make a living by what we get. We make a life by what we give."

"Don't ever doubt the importance of your help through NIED.

It is absolutely key. Thanks to you and NIED, many girls will find their way back to a healthy and fulfilling life. Hopefully, along the way, some of them will return to you and choose to get involved in this critical and immense task."

"I want to congratulate you on the incredible work and your significant accomplishments!

I didn't realize the extent of your organization until I read the impressive information that you have on the website. Amazing and wonderful!!"

- F. K.

## Contact Us

We'd love to talk to you more about our programs and impact.

info@nied.ca • nied.ca











